

**THE MINNESOTA GOVERNOR'S  
COUNCIL ON DEVELOPMENTAL DISABILITIES**

*Stories*  
**OF LEADERSHIP**

## Foreword

*O*n May 1, 2002, the Minnesota Governor's Council on Developmental Disabilities celebrated the fifteenth anniversary of its Partners in Policymaking® program.

The first class began with thirty-five adults with disabilities and parents of young children with developmental disabilities, and has now grown to over 9,000 graduates in the United States and the United Kingdom.

In our invitations to Ed Roberts, Gunnar Dybwad, Lotte Moise, and Dolores Norley to speak to the group at that first weekend of Partners in 1987 we wrote:

“We are selecting people who are highly motivated, fairly young, and intensely interested in developing into a dynamic, well-informed group that can lead policymaking into the 21st century.”

The first class did, in fact, lead the way.

The success and expansion of the program occurred because so many outstanding people became allies and supporters. Each person worked hard to find funding and assure that the program kept its integrity. We extend our deepest thanks to all those who made the program a success.

Linda Beauvais, our graphic artist, and Ann Marsden, our photojournalist, have watched the transformation of people in our Partners program and urged the production of a book that would tell the inspiring stories of Partners graduates. We are thrilled with their ideas and perseverance.

Lee Roberts, a local journalist, made a one-year commitment to travel to all parts of Minnesota to interview people. He pursued stories with intense interest.

Lynn Marasco, a local editor, was invaluable in weaving the spirit of each individual throughout the stories and making them almost jargon free.

Mary Jo Nichols, our grants administrator, handled the logistics to make the book a reality.

We have more stories than space. Many of the individuals featured in this book graduated from Partners ten years ago but continue to be active leaders. We will share recent success stories through our Web site and e-learning site currently under development.

We hope you enjoy this book and will pass it on to others.

A handwritten signature in black ink that reads "Colleen Wieck". The script is fluid and cursive, with the first letters of each name being capitalized and prominent.

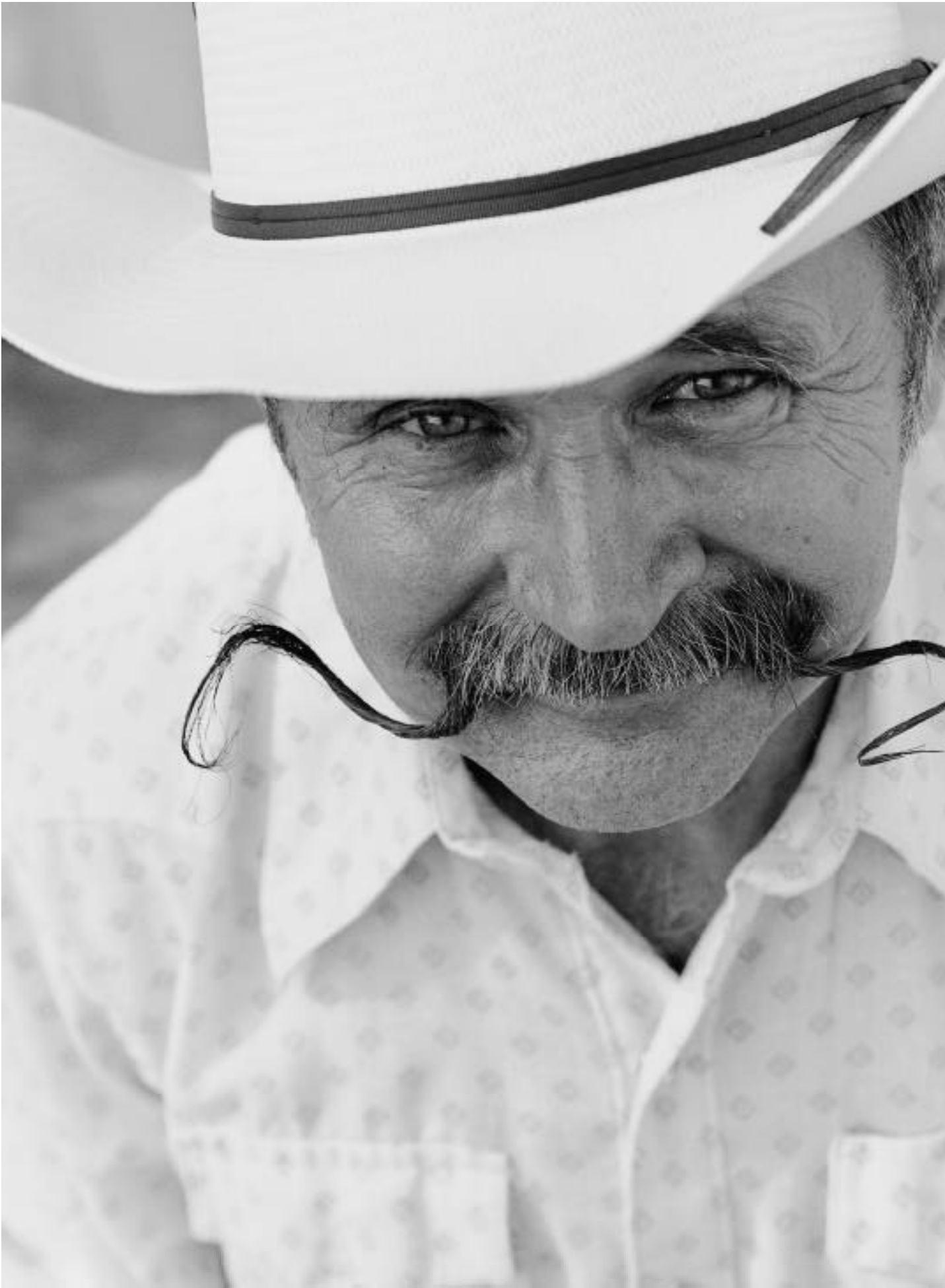
Colleen Wieck, Executive Director,  
Minnesota Governor's Council on Developmental Disabilities

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# Dwight BARRICK

was once a farmer and family man. Then he was the widower and single parent who gave up farming to care for a son with cerebral palsy. And now there's Dwight Barrick the activist.

The transformation came about through the Partners in Policymaking program. Dwight's wife, Marlene, had looked into the program before she died of cancer, and Dwight, left to care for their son, signed up. At the Partners weekend on education, Dwight realized that Joel wasn't getting a good education.

"Government regulations set up a way of doing things, and the school bends things to their wishes rather than the children's needs," Dwight says. "They hide behind that excuse of ignorance, but they know what their responsibilities are. It's just that as long as they can keep putting someone off, they will."

The schools didn't see Joel as a potentially productive person, Dwight says. During Joel's eighth-grade year, for instance, the school didn't want to teach him math because, they said, the concepts were too confusing for him to learn.

And they said that Joel was disruptive, that he couldn't sit still in the classroom. "At my Partners weekend, someone talked about positioning," Dwight says. "I went to the school and said, 'Positioning.' About two months later the occupational therapist finally said that Joel's feet were an inch and a half off the ground. Simple. You get a two-inch footstool. Problem solved. Joel's OK in class now. You can't sit in class when you're uncomfortable. Nobody can."



For Joel, right, being with horses is a natural and delightful experience that brings much calm to his life.

Dwight and Joel are great sidekicks, reminiscent of duos in cowboy lore and old movie fame.



After retaining a legal advocate to fight for his son's rights—and winning—Dwight became a leader, a teacher, and a supporter of other families. He started a support group for parents of children with disabilities to replace one that had collapsed a couple of years earlier. “I felt there was a need,” Dwight says. “We’ve got 240 kids receiving special education services in our school district. We got a grant, and got a brochure out there so that more parents know to come and find out what’s out there for them to make life a little easier.”





# JoAnn BOKOVOY

knows that the more people realize the benefits of including folks with disabilities in society in whatever ways we can, the better off we'll all be. "If we hope to make things different for kids fifty years from now, we need to work now. Change is slow. Too slow!"

JoAnn recently resigned from her job and started a personal care attendant agency. For now, her only customer is her son Brad, who is in his late twenties. Later, JoAnn plans to hire other attendants and work for other people with disabilities.

"The work my heart is in is always trying to find a better way for folks with developmental disabilities," JoAnn says. "The most important thing for an attendant service is understanding people and providing for their needs. I will never be someone who just runs an agency and hires people. I will be a hands-on administrator."

None of this was in JoAnn's mind before Brad's first brain tumor. "Brad was an athletic, smart, sweet kid," JoAnn says.

"Then he got a brain tumor and lost his vision and his short-term memory"—and spent nearly three years fighting for his life. He battled through brain tumors again when he was eighteen and twenty-three.

Shortly after Brad's first tumor was removed, JoAnn learned the tools of effective advocacy in the Partners in Policymaking program. She had naively thought that American society takes care of people with disabilities but experience taught her otherwise. She has been working toward a better world for people with disabilities ever since.



JoAnn and her son Brad are close. She takes her role as PCA very seriously, but never forgets she's a mom.



JoAnn laments the fact that many groups that serve people with disabilities pay their administrators six-figure salaries, while those who actually do the work get about six dollars an hour. She adds that most groups that should serve really don't serve.

JoAnn looks forward to working with people who need her help:

"It's exciting and it feels good to have an opportunity to give it my best shot," she says. "If enough of us give it our best shot, we're going to make a difference. What's important is working in the right direction."



# *Claudia*

CARLISLE believes that Partners in Policymaking made her confident. So confident that now she can go out into the world and make changes. “It planted a seed,” she says. Claudia, who has cerebral palsy, wants to make this a better world for people with disabilities.

“We need to get out into the community and show people we have smarts and intelligence just like they do. If I let my disabilities get the best of me, I would just stay home and watch TV.”

After many years of struggling to have an independent life, she now lives in a house that she and Jim, her partner-for-life, designed and had built.

“It’s a never-ending battle,” she says. “Even my speech is becoming a big issue for me. I don’t know if it’s because people are in too much of a hurry to listen, or that they don’t like what I’m saying.”

As a child, she was taken out of an unhealthy home situation and placed in a boarding school for people with disabilities, where she had many difficulties.

She quit school and put herself into a nursing home. A vocational rehabilitation counselor helped Claudia improve her language skills and steered her toward the greater opportunities available in the Twin Cities.

“She thought I was wasting away in the nursing home,” Claudia says. “She said I had a lot more potential than I was being given credit for.”

An agency helped Claudia find housing and personal assistance in the Twin Cities. At first she lived with five other people, and then with just one. In the end, though, Claudia wanted to live on her own.

“People told me not to do it, that I’d be too lonely, but it was the best decision I ever made,” Claudia says. “My goal, ever since I could talk, was to live independently. People said, ‘Forget it, you can never do it.’ I did it for five years.”

During that time, Claudia put herself through community college, where she studied human services. “I had difficulty with learning,” she says. “I worked my tail off to graduate. The college thought I was nuts for even wanting to try. But my determination made them want to help me get through it.”



Claudia’s wheel-chair means everything to her. It is her means of independence, but sometimes, it would be nice if it were more like a love seat, built for two!



Claudia met Jim at a square dance club for people with disabilities. They have complementary skills—she is stronger physically and he has stronger intellectual ability—but they still face plenty of challenges. Both need help in daily living, and they have had problems finding good personal care attendants. Agencies get a big cut of the medical assistance money earmarked for attendant care, “which means the attendants don’t get any money,” Claudia says. “They can go to McDonald’s and get better benefits and more pay, and have less responsibility.”

Claudia and others successfully lobbied the state legislature for passage of a program that allows people who need attendants to recruit and hire their own: there’s less overhead, and the attendant gets paid more.

As a member of the Minnesota Governor’s Council on Developmental Disabilities and its public policy committee, Claudia offered this challenge—one that she has taken up successfully herself:

“Self-determination is the belief one can achieve goals that few others think possible. Through this conviction, creative decisions and unusual choices can be made (guided by innovative support groups if necessary) to get one’s destiny far beyond society’s expectations.”





# Sharyl DOWNWIND

thinks other countries are way ahead of us in terms of valuing children—including children with special needs.

“In the United States, minority children with disabilities get the lowest priority,” she says. “I want things changed so that what happens is what’s in the best interests of these children, not what’s in the best interests of the state or the county or even the parents. I want the children to have a voice and to have rights. That’s my long-term goal.”

Despite a reservation childhood that embodied all the negative stereotypes of American Indians, Sharyl takes pride in her heritage.

Following her own battles with family dysfunction and alcoholism—she herself became sober more than twenty years ago—Sharyl resolved to help the community by being a foster parent. She saw how sparse services were for Ojibwe people in rural areas and on reservations, and she knew grassroots changes were needed.

American Indian culture values “listening and being quiet, which are good qualities,” says Sharyl. “But where that hinders us is that people aren’t out there asking questions and being assertive. That seems to come a little bit easier for me, so maybe that’s what I’m supposed to do. I went to Partners in Policymaking with the idea that I was helping my biological son and my foster children, but also thinking that I needed to bring information back home to share with other people, particularly the three reservations around here: Leech Lake, Red Lake, and White Earth.”

She soon became coordinator of Our Children Are Sacred, a Partners outreach program on the reservations. Weekly support groups and monthly workshops are aimed at increasing access to disability services and greater empowerment.

“If kids with spina bifida, cerebral palsy, and fetal alcohol syndrome get the right services when they are young, the potential outcomes are much more positive,” she says.

Partners in Policymaking led her to speaking engagements throughout the United States and Europe. She has spoken in Ireland about how to care for children with fetal-alcohol effects.



Motherhood hasn’t always gone smoothly for Sharyl, but she couldn’t be more committed or courageous in her advocacy for her children and many, many others.



“I’ve been given some opportunities to be heard and maybe make a difference,” she says. “I feel a strong responsibility to do these kinds of things, like that’s what my purpose is.”

Sharyl participated in the Partners program at a time when she was battling for health care for her foster daughter Keisha, and for her son Bradley Bear who was born with cerebral palsy. Doctors felt that Keisha, who had fetal-alcohol-related disabilities and used a wheelchair, would improve dramatically if she had spinal surgery. Medical assistance turned down the surgery.

With what she learned at Partners and the help of the Minnesota Disability Law Center, Sharyl sued the state and won the appeal. Keisha can now dress herself, do most of her own personal care, and walk with a walker.

“That was just the beginning,” Sharyl says. “After that there were more surgeries, more services, and some equipment that she needed. Because I knew what I was doing then, it came a lot quicker”—she snaps her fingers for emphasis—“and they also knew that I knew what I was doing, so they quit jerking me around so much.”

“Partners made a massive difference in our lives—for Keisha in particular, but also for all of the other children I had at the time and had placed with me after that, and for my biological son. Now I’m coming at things knowing much better how to find out what’s wrong and what I can do about it and where I can go to get help.”



# Duluth

is home to a strong community of self-sufficient people with disabilities. More than fifty members of the Duluth chapter of People First, an advocacy group, regularly attend its meetings.

They choose their own leaders, set their own agenda, and promote positive changes for people with disabilities in their community. They meet, write letters, make phone calls, and negotiate for improved transportation, health care, and public services. They have jobs and do volunteer work.

Many of these leaders share another similarity: they have all graduated from the Partners in Policymaking leadership training program.

It started when Jenny Kempfert, an advocacy coordinator for Arc Northland (which provides advocacy, support, and education, and facilitates the People First program), received a notice about Partners in the mail. She discovered that Arc Northland administrator Lynne Frigaard had gone through the first-ever Partners class and highly recommended it.

Kempfert recommended Partners to two People First members, Peggy LaBlanc and Lloyd Goodman, who returned from Partners raving about the program. Nine people from Duluth have now attended Partners, and all have played important roles in their community.

Partners graduate Betsy Dentinger is a past president of People First, and Goodman served as vice president and president in previous years. Since Goodman and LaBlanc attended Partners, the People First group has grown with an increased interest in Partners.

The group is active in the community, working with the city and the Duluth Transit Authority (DTA) to resolve issues that affect them. Linda Markle, for instance, has written several letters to the editor of the *Duluth News-Tribune* and to the DTA. "I never would have done it if I hadn't been through Partners," Markle says. "I would have been too shy or too scared. But now I get a paper every day and I read the editorials and the letters. If I see something, I'll write a letter to the editor."

When a shuttle bus route that had provided service to three Duluth malls and other large merchants was dropped, Markle wrote a letter telling the DTA the route was important, in part because, without it, people had to cross a dangerously busy road. She didn't get a response, but the DTA is said to be planning to reinstate the route.

Opposite page,  
left to right:  
Peggy LaBlanc,  
Dorothy Somppi,  
and Linda Markle.



“A few people who have been through Partners are emerging as leaders in the [People First] group, Linda Markle especially,” says Kempfert, who is now associate administrator for Arc Northland. “She’s a strong person anyway, but she has blossomed since she went to Partners. Her innate leadership skills just needed to be brought to the surface. She suggests a lot of things at meetings, and they get done.”

LaBlanc has also been a valuable asset, Kempfert says. She offers to help others based on what she learned at Partners, and she has become a much stronger advocate for herself. She petitioned her boss until she received a new chair that would allow her to work more efficiently.

“Partners helped me say what I need,” LaBlanc says. “It made me stronger, made me grow. Now I get to be whatever I can be. I don’t sit back. If I want something, I’ll get it.”

When Goodman saw that Arc was sending letters that referred to “people with mental retardation,” he asked the board to use “people with developmental disabilities” instead, and they did.



“With both Lloyd and Peggy, I saw real personal growth in them through going to Partners,” Kempfert says. “I am in awe that they have done what they’ve done. At first, their staff was extremely reluctant to let them go to St. Paul on their own.”

“I’m able-bodied and I can help, so why not help the people on the bus?” LaBlanc says. “I can read, so why not help people to read? I won’t read it for you, but I’ll help you and help you to learn. Maybe they won’t learn if you do it for them, but if you teach them, they will learn. That’s what I learned through Partners.”

Partners made Dorothy Somppi stronger, she says. She has confronted people who were making fun of her or her friends. When somebody made fun of a friend in a wheelchair, she said, “Hey, how would you feel if you were in her



The far reaching People First program inspires friendships, community, education, and getting people the services they need.

Arc Northland administrator Lynne Frigaard, Partners graduate, left.

body? It's not right." The person backed off. In a recent feature in Arc Northland's newsletter, she talked about the Partners in Policymaking program and offered to help anyone who is interested.

Taken individually, some of these actions may seem small. But they build, one on top of another. The more people who are educated about developmental disabilities, by people with developmental disabilities, the less ignorance there will be. The more hope there will be. The stronger a community will be.

Society used to throw away people with disabilities, thinking they were worthless. Peggy LaBlanc, who was born in 1951, was placed in institutions in Cambridge and Brainerd throughout her childhood, even though her parents fought to keep her at home. "It was terrible," she says, "like a prison. Every time I did something wrong, I got locked up. I got locked up a lot. Solitary confinement. It was terrible." The staff was largely indifferent. For the most part, she didn't get an education. "They told me they didn't have a special school for me," she says.

Now LaBlanc wants to build a strong community in Duluth for people with developmental disabilities. This is what burns inside her: Make change now. Make things better. Make people understand who I am.



# Bonnie<sup>•</sup>EATON

wants to make a difference. “If I can help people follow their dreams, and become what they want to be, well, that’s pretty important to me,” says Bonnie, an educator, advocate, and friend of people with disabilities.

When Bonnie’s brother Ordean Rosaasen, who has developmental disabilities, was growing up, he was expected to work hard on the family farm just like his brothers and sisters. Bonnie never looked at him as a person with a disability—he was just her brother.

Things were different at school. Ordean was essentially locked in a small, dark room. It wasn’t until he was fourteen—and had been moved to another school district through the dogged persistence of his mother—that he learned to read.

“They didn’t think these kids would be productive, so they just put them in a room and they just sat there,” Bonnie says. Once Ordean went to a different school, “it was amazing. This kid just absolutely changed from being a shy kid to

having self-confidence. That was from having a wonderful teacher and from people giving him a chance to prove that he could do something.

That's how I got interested in working with people with disabilities."

Bonnie was an advisor for a self-advocacy organization for people with developmental disabilities; there were seventy-five people at the first meeting. She teaches self-advocacy and job skills, and she supervises workers who clean hotel rooms.

Bonnie attended Partners in Policymaking after Ordean participated and then convinced her to go. It has given her the ammunition to work the system on behalf of people with disabilities.

She writes letters, and she calls legislators and the governor when legislation concerning people with disabilities is up for discussion. "I never would have done this before," she says. "I'd probably be in the same field of work, but I never would have gotten into the political part. It just didn't dawn on me to think that one letter would make a difference."



Bonnie's vision and commitment have made her a strong advocate and educator.

In addition, she is now the primary caregiver for her grandchildren.



Now she drives people to the state capitol to visit with their state representatives and act as their own advocates. She passes on information she picked up in Partners to others in the community.

With the degree in social work she's working on, "maybe I can have more power to help others," Bonnie says. "The more I learn, the more I can pass on. Things are getting better for everybody. We may have a long way to go, but we've come a long way, too."

It's sometimes difficult for a worker with a disability to get a foot in the door, Bonnie says, but once the work starts, everything usually goes well. The key is getting people to see what people with disabilities can do instead of what they can't do.

"We have special needs, and people are wary," Bonnie says. "But after we make it over the hurdle, they find out that we're able to do the job. It takes these workers a little longer to learn the job, but once they learn, they do it well."

Through their work, Bonnie says, her employees learn that they have choices and power, and they appreciate the opportunity to prove that they are productive.

"The paycheck is very important," she says. "They love getting it every two weeks. They know the amount of money they're going to get, and they're thrilled. It gives them a lot of self-esteem. They feel important."

She contemplates what she has just said and adds, "I love my job."



# Gary ELLIS

is an advocate and a dedicated believer in activism. When his daughter Anne was born with multiple disabilities, Gary didn't spend a lot of time feeling sorry for himself. Instead, he got to work. He knew he could advocate for the things Anne would need, because he had already been an agent for change in his small Minnesota hometown and during his activist years in college.

Activism is a way of life for Gary. "You just go on advocating for good causes," he says.

Today, Gary not only works toward improving Anne's life but also is executive director of a group that provides affordable housing in the Twin Cities metropolitan area.



Gary learned about activism through his mother, a schoolteacher who organized and led many teacher initiatives. His greatest learning experience at college—in terms of preparing him for raising a child with disabilities—was working as an orderly at University Hospitals.

“I worked in the rehabilitation wards, and at that time they were pushing people to get out into the world,” Gary says. “My thinking was developed to see the possibilities for people with disabilities. I was in contact with some people who were pretty progressive about this stuff, so when Anne was born I had a little understanding of what the possibilities were for her.”

When it was time for Anne to go to school, Gary pushed for her to be integrated into regular classrooms. Until then, children with disabilities had been sent to “cluster” sites, where many special education students attended



“I don’t want people to take me so seriously,” Gary told photographer Ann Marsden.

He’s focused on expanding the possibilities for special needs kids; but joyful moments with his daughter, like this one on their sun porch, are his true rewards.



school but were separated from their peers. Anne was the first child with severe disabilities in her school district to attend her neighborhood school, Gary says. Though he had had plenty of experience in advocacy work, he gained depth of understanding and confidence through Partners in Policymaking. “It was transformational in terms of understanding everything,” Gary says. “I was focused more on my daughter’s issues, but it got me beyond that, out to the world as a whole. You’ve got to give back. You can’t just be asking for stuff from the school district or the city. You’ve got to be willing to do your bit when you’re called.”

Gary has been president of Arc in Ramsey County and has served on state and national Arc boards. He also helped form groups that fought to close Minnesota state institutions that isolated people with disabilities. He has served on a special education advisory committee and on an accessibility task force.

“Anne herself makes me proud,” Gary says, “and it makes me proud to realize that we’re probably the first generation in the history of the world that has brought kids with severe disabilities into society. That’s a tremendous accomplishment.”



# *Karen* GORR

got the chance to survive, and she didn't waste it. She would have died, she thinks, if she had spent much more time in the State School and Hospital for the Feeble-Minded in Redfield, South Dakota. Her older brother died there.

Karen, who has cerebral palsy, had spent ten and a half of her thirteen years in Redfield when she got her chance. Karen's mother, Mabel, convinced the institution to let Karen come home for the summer. Mabel told Karen that if she learned to walk she might be able to stay at home instead of returning to Redfield in the fall.

"I went for it," Karen says today, more than fifty years later. She taught herself to walk, escaped the institution, and went on to graduate from high school and college to become a teacher, marry, and raise a daughter.

"Redfield was a horrible experience," Karen says. "It was a prison." The windows were barred and the doors were locked. Karen was beaten with a paddle for minor wrongdoings, sometimes for things she hadn't done.

Anyone who really acted up would be sent to the basement, where people with the most severe disabilities were left in cold, dank surroundings, often without any clothes, to scream, moan, and fight.

At mealtime, Karen was allotted only fifteen minutes to eat—too short a time for her. People who didn't eat everything on their plates suffered the consequences, so Karen would clean her plate, but the food didn't stay down.

When she was at home with her mother that summer, Karen had time to eat, which helped her gain strength and in turn helped her learn to walk.

"I was the best little girl, cooking and keeping the house clean," she says. "I didn't ever want to go back to Redfield again."

She ended up staying home with her mother and going to a country school. Karen started in the third grade at age thirteen, graduated from high school when she was twenty-one, and went on to earn a degree in elementary education. While she was in college, she worked for South Dakota's governor, Joe Foss, as a live-in attendant for his daughter, who had cerebral palsy.



Strength and resolve poured out of Karen when she left the institution.

The possibilities became very real and now, with Partners, the possibilities are boundless.



Karen told the governor's wife about the horrors of the institution at Redfield, and the governor soon paid a visit. Shocked by what he saw, he mandated changes that made life better for the residents.

Karen came to Minnesota in the early 1960s to take a teaching job. While she was teaching special education classes, she became the first teacher to integrate children with disabilities into the physical education curriculum with the other students. She was the local Arc president and served on the United Cerebral Palsy state board, as well as two terms on the Minnesota Governor's Council on Developmental Disabilities and several other committees.

During her time on the Governor's Council, she attended the Partners in Policymaking program in its inaugural year. Partners, she says, empowered her with information and emotional support. Today, she occasionally speaks to high school and college classes about her experiences at Redfield.

Karen learned long ago not to harbor bitterness toward the people who worked in the institution, or toward her mother, who put her and her brother there.

"She still thinks I'm mad at her for putting us in the institution," Karen says. "No way. She was holding two jobs to survive, and she couldn't even get a babysitter for us. People in that town thought we were freaks of nature. My mother didn't have any choice."



# *Kurt* GRENIGER

believes that advocacy is either just a word you use or it becomes a part of you. “It beats within my heart,” Kurt says. To be able to educate someone who’s never been around people with disabilities...well, Kurt knows it makes the world better for us all.

An injury that resulted from a fall during a high school wrestling match left Kurt paralyzed from the waist down—and angry. “I didn’t like the able-bodied world, period,” he says. “You people get to walk, and I didn’t get to anymore. It wasn’t until I was twenty or twenty-one that I really accepted what had happened.”

A college wheelchair basketball team coach recruited Kurt, got him to start lifting weights, and inspired him to quit drinking. While Kurt was a starting guard in college, his team won two national championships; the second time, Kurt was team captain and was named most valuable player in the title game. After college, Kurt was recruited to the U.S. Junior Olympic team. He won three gold medals at a national wheelchair track and field championship, earning a trip with the U.S. team to the world championships, where he was on a gold-medal-winning, world-record 4 x 4 relay team.



“It was always a dream I had, that I could go to international events,” Kurt says. “I was a national wrestling champion when I was in seventh grade. By the time I was a freshman in high school, a university wrestling program had already contacted me. I aspired to be an Olympian.”

After playing for a decade for a wheelchair basketball team, Kurt started his own team and a nonprofit group that promotes wheelchair sports.

In his first job, at Honeywell, as a member of the company’s access council, he used his mechanical engineering skills to improve the workplace for people with disabilities.



Kurt is a rich man. His love of family, career, and athletics makes him grow even richer everyday.



As a result of participating in the Partners in Policymaking program, Kurt received funding to create, produce, and host a public access television show called *Diversability*. The program's goal was to explore public policy and disability topics. Sally Koenecke, whom Kurt met in his Partners class, co-produced and co-directed; James Anderl and Connie Johnson completed the production team.

Proud of what he has accomplished and grateful that he found a direction, Kurt credits values ingrained in him by his family.

"They gave me determination to succeed," he says. "My mother and father were very successful people in their own ways. They always wanted us kids to have an education. After I was injured, they got across that having a disability doesn't mean you can't have everything in life that you want."



# Sharron

**HARDY** declares that “uphill battles exhilarate me, most of the time.”

Born with cerebral palsy, Sharron is a longtime advocate for people with disabilities, spurred on by a mentor, her mother’s faith, and the lessons she learned from the Partners in Policymaking program. Politics isn’t a dirty word to Sharron, who has been politically active since the 1960s. She has been fascinated with politics ever since she can remember, and she earned a degree in political science at age thirty-six in the 1960s; her high school counselors told her she wasn’t college material, even though she had a B average. She has been involved with local politics and served on the boards of numerous advocacy groups. Her passionate advocacy has affected people throughout her community and the state.

“There are many people in the disability community who, through no fault of their own, can’t do it as well as I can,” Sharron says.

“I feel a sense of obligation about doing that for as long as I am able.”

The incidence of polio was high in 1946, the year Sharron was born, and she was misdiagnosed for a long time before she found out she had cerebral palsy. Doctors told Sharron's mother to put Sharron in an institution because she would never amount to anything, but her mother disregarded them. Sharron attended—and enjoyed—a school for children with disabilities. When she was thirteen, she and five other students transferred to the public schools.

“It was the first time that kids with disabilities were integrated into the Minneapolis schools,” Sharron says. “We were guinea pigs. I’m glad I went through it, but socializing was difficult. Kids without disabilities weren’t mean; they just kind of ignored us.”

Just out of high school, Sharron found a mentor. “Micki Schroeder had polio,” Sharron says, “and I was in a wheelchair too. Micki said, ‘If you want to follow me, I’ll show you the ropes.’ So I did. When she passed away, I felt even more that I had to do what I could to help others. Micki helped make a lot of positive changes for people with disabilities, even things she didn’t need herself.”



Sharron is a serious person, and a natural political advocate who is destined to share her strength with others.

That's what makes her life so joyful.



Sharron has been on the Legal Aid Society board for ten years. She always makes sure that she is a delegate to national conferences on improving services to Legal Aid clients because, she says, “I want to have someone there who visibly has a disability.”

She has been active in setting transit system policy regarding people who aren’t able to use regular buses. Her part-time job is instructing professional drivers about the Vulnerable Adult Act specifically and about disabilities in general.

Sharron jumped at the opportunity to attend Partners in Policymaking. “I’ve been to a lot of seminars and courses and groups,” Sharron says, “and Partners was the best. It gave me a lot more knowledge of the political process. I thought I knew a lot about politics, and then I discovered how little I had known.”

Partners also rejuvenated Sharron’s spirit. “I was in what they call ‘advocacy burnout,’ ” she says. She’d been at it for more than twenty years, and “we just weren’t experiencing enough wins,” Sharron says. “Partners reinforced my beliefs and energized my whole outlook about advocacy.”



# Debbi HARRIS

is no stranger to discrimination.

“My whole life people have made assumptions about me, and I’ve spent my whole life trying to prove that they weren’t true.” Debbi learned long ago from her family and from her experience of the world that the way to beat prejudice was to excel at everything she did and to fight as if her life depended on it.

Even so, she was astonished by the discrimination her son Josh, who was born prematurely with a brain hemorrhage in 1993, encountered in the worlds of medicine and education. Debbi has more than once threatened lawsuits to gain basic rights for her son, rights that others take for granted.

Early on, doctors had criticized Debbi and her husband, Victor, for their decision to allow Josh to live. “They wanted us to take the first opportunity to just let things go, and that felt real wrong to me.”



When Josh got an upper respiratory infection in the neonatal intensive care unit, a physician asked Debbi to sign a do not resuscitate and do not intubate order. A neurosurgeon suggested that the Harrises visit state institutions and “get a look at these kids with watermelon heads.”

Debbi knew from her two older sons what it feels like to have a baby be responsive to her love and caring, and she felt that same responsiveness in Josh. Yet when Josh hit vulnerable spots—and there have been many—Debbi was made to feel almost ashamed for wanting to keep her son alive.

Schools, too, “have wanted to take the easy way out,” Debbi says. She threatened a class-action lawsuit to bring the district’s policy on nursing care for students with disabilities into compliance with the law. When the state investigated a complaint she filed against the schools, violations were revealed.



Debbi’s older sons are as committed to Josh as Debbi is; the support is great and necessary since her husband is sometimes on active military duty.

Josh, shown with one of his brothers, opposite page, center photograph.



Wanting the best for Josh led Debbie to pursue a degree in health care administration, and she was appalled by the discrimination against people with disabilities that was prevalent among some of her classmates—people destined to be running hospitals.

Now nine, Josh uses a wheelchair, has a feeding tube, has a trach, is quadriplegic, and has cerebral palsy. He points with his eyes, has signs for yes and no, and expresses disapproval by saying “uh-uh.” He’s a regular spectator at his two older brothers’ hockey and soccer matches.

“When everything happened with Josh,” Debbie says, “my dad sat me down and said, ‘You know what? Life isn’t fair. You may never know why this happened, so you make the best of it.’ And he was right. There aren’t any guarantees. You just work with what you have and be thankful that it’s not worse than it is.”

“One day Josh and I were standing outside Children’s Hospital and a woman said, ‘Is he yours?’ I said yes. She said, ‘Oh, I’m so sorry.’ And I said, ‘Why? We’re standing outside the hospital not inside, and we’re doing well!’ You just have to put things in perspective.”



# *Brian* HEURING

is captivated by children—their humor, energy, innocence, and acceptance.

“They’re so cute,” he says. “It makes me laugh. There is one kid I really like, because he asks me to sit with him, and he’s never had a real dad. I almost love him like a father loves a son.”

Brian has what he calls a “dream job” as a teacher’s aide at a day-care center. Teachers, camp counselors, classmates, and bosses haven’t always appreciated Brian—but he’s too busy living his life to worry about them. He believes he has been blessed.

He lives in his own apartment, pays his own bills, advocates for people with disabilities, and aspires to do more.

Brian credits his ability to live independently, and to follow other dreams, to the Partners in Policymaking program. What he learned in Partners changed his life—and his family’s life.

Brian's mother, Sharon Heuring, attended Partners classes with Brian to help him interpret the material, which was sometimes challenging for him because of his autism. What she learned transformed the way she thought about her son.

Before Partners, "I didn't trust him out of my sight," she says. "I didn't know how capable he was. We needed a new way of thinking. If we hadn't gone to Partners, he would have been in a sheltered workshop and in a group home."

To which Brian quips, "I'll live in a group home only if I can be on the staff."

Before he went to Partners, Brian says, he never even considered that he might one day live on his own in an apartment. The program helped him to see the possibilities that were open to him.

In the community, Brian promotes a better life for all people with disabilities. He is a member of People First, has spoken about autism at a local church, led a panel discussion at a meeting of the Twin Cities Autism Society, and has been a speaker at several conferences.



Brian, shown here with his mom, loves life and sees possibilities everywhere.



“He’s paving the way,” says Sharon.

The “disability” label brings out biases in many people, Brian says.

He used to work at a grocery store, then at a sandwich shop, where his boss was particularly tough on him.

“If most people make mistakes, they say, ‘That’s OK. Everyone makes mistakes.’ If I make a mistake, they think I am incapable,” Brian says.

He’s not bitter, though, and he feels more sorrow than anger toward people who have mistreated or misunderstood him.

“If you don’t even give me a chance, you’re the one missing out,” Brian says cheerfully. “You’ll find out I’m a great person.”



# Connie

KOTONIAS has come a long way since the night she came home and found her three-month-old daughter acting strangely. It was obvious that something had happened to Micky while her dad was watching her.

Micky, who is now in her twenties, was abused by her father—abuse that resulted in severe disabilities. Yet her ebullient spirit has touched many people: she is a volunteer at a hospital and a nursing home, and she helps clean at an assisted-living facility.

“She has found places where she can give back,” Connie says.

“She is a person who takes a lot of resources—people have pointed that out to me her whole life—and if you take, you should give back.”

Although Connie is glad that she and Micky didn’t abandon their hometown roots, there was a time when a you-allowed-this-to-happen attitude in their northern Minnesota community made it tempting.



Doctors thought that Micky's father had been abusing her over time. "It was shaken baby syndrome," Connie says. "It wasn't like he lost control one time and did something he regretted forever. It was going on for a couple of months before we figured out what the problem was. I feel a lot of guilt about that. I didn't do anything wrong and Micky didn't do anything wrong." Micky now lives in a house that was once her great-grandmother's.

An early childhood special education teacher, Connie was attracted to the Partners in Policymaking program at a time when, as a parent, she was at odds with the school system. She was intrigued when she saw a change in a friend who also had a child with a disability: "She came back from the Partners program a calm person," Connie recalls.



A life full of love and joy is Connie's mission for her daughter and herself.

Healing and growing stronger every day, Connie and Micky are making their goals a reality.



The program had much the same effect on Connie. “All of a sudden I could step back and look at the process and see what was going on,” she says. “I’m not saying I wasn’t emotional, but I was able to be more critical of how I was approaching things, and I lost the anger.”

After years of battling school administrators, Connie now trains many to be creative on behalf of other kids with special needs, and she has helped hundreds of parents to work with their children’s schools.

“It’s fun now because people come up with creative things that I couldn’t have even begun to think of,” Connie says. “Everybody has learned to think outside the box.”



# Richard MATHISON

is helping to give back names to Minnesotans with disabilities who died in institutions. Through a project called *Remembering with Dignity*, numbered gravestones are being replaced with markers inscribed with the names of the people who lie in these graves, and the dates of their birth and death.

Richard became involved through a self-advocacy group called Advocating Change Together (ACT), which helped start the *Remembering with Dignity* project. He sees this work as a single drop of water in an ongoing river of self-advocacy.

“I get a thrill out of helping people know how to stand up for their rights,” Richard says, “and helping them to learn that they can make the right decisions and feel good about themselves. Then they can train others and bring them into the self-advocacy movement.”

In 1983, ACT representatives spoke to a committee Richard chaired at Minnesota Diversified Industries, where he has now worked for more than thirty-two years. Inspired by the visit, he has been an ACT activist ever since; he has served five one-year terms as the group's president, and has also been vice president and treasurer.

To close all institutions for people with disabilities in the United States, was one of ACT's primary goals. "All of the institutions in Minnesota are now officially closed," he says. "All of them."

His advocacy work has earned him invitations to conferences all over the country, from Alaska to North Carolina and from Massachusetts to Colorado. He was the Minnesota representative who signed a national self-determination declaration for people with disabilities.

"I dream that people who don't have disabilities take a good look at us," he says. "We're people first. Just because we have disabilities we shouldn't be treated badly. They should be more supportive of us, giving us a chance to live a better life, instead of being put into group homes or reopening the places we've closed."



Richard is a devoted guy... to his mom, opposite page right, his friends, and community.

He works hard at his job and is committed to the central issue—that people with disabilities get treated with respect.



Participating in the Partners in Policymaking program gave Richard abundant information and strategies for getting things accomplished.

Richard's activist roots go back to his youth. In grade school, when a teacher forced him to jump on a trampoline, he broke his arm. In high school, classmates made fun of him because, he says, he was slow.

"When they poked fun at me, I said, 'How would you like it if you were in my place and people poked fun at you?' They didn't appreciate that. Then they backed off. They thought about it before they said anything, because they sure didn't want to be poked fun at. They don't have the right to do it to me or any people with disabilities."

Hearing about the nameless graves at the institutions upset Richard, and he joined with others to take action. They asked for an apology from the state legislature for the treatment of people with disabilities in state institutions, but none has been forthcoming.

Even if they receive no apology, Richard is helping to overturn the legacy of the past by creating a better future for people with disabilities.

"Life for me is a lot different than it used to be," he says. "People in society take a good look at me. I know what I'm doing and I can stand up for my rights. Then they back off and maybe they think...this guy knows plenty."



# Brian<sup>•</sup>MENZE

likes to ask the questions, “Where does disabled stop and supposedly ‘normal’ start? Is there a cutoff point? People who can’t see to drive after dark are restricted, but is it a disability? My son can’t have a conversation, yet he can get what he needs—in some way he is able to ask for it.

Do I consider him disabled? No, I don’t.”

Brian thinks of his nine-year-old son Jakob—who was diagnosed with autism at age three—as someone who doesn’t talk much and needs more than the typical amount of structure and routine.

“I do not consider people who cannot take care of themselves, but do lots of other things, disabled,” Brian says. Schools and public health agencies in Waseca County do. They consider Jakob disabled, and Brian has had to strongly advocate a change of opinion from time to time. Parents shouldn’t go to schools and health systems begging for crumbs and be thankful for whatever they get, Brian says, because they are legally entitled to more than they realize.



He also thinks bureaucracies are so concerned about short-term spending that they cannot see benefits or future savings.

“The whole system says, ‘We’re going to let you have this because you have a child with a disability.’ No, you’re going to give this to me so that you don’t have to institutionalize him when I’m gone,” Brian says. “To me, it’s not a handout. It’s an investment now to save money later.”

Once Brian told one of Jakob’s teachers that only a parent and two school representatives are needed to make an individual education program (IEP)—an agreement between the schools and the parents of a child who receives special education services—legally binding. A principal or superintendent who doesn’t attend an IEP meeting and then later objects to the program is powerless to change it. Since then, either the principal or the superintendent has attended every one of Jakob’s meetings.



Brian and his family, shown on the opposite page, love nature and history.

“Those are the tools we use to help educate and inform others regarding people with disabilities. And they work!” Brian says.



“Nine people were at three meetings, lasting over ten hours,” Brian says. “Most of these meetings have the parent, maybe the special ed teacher, and the classroom teacher, and that’s it. And it’s twenty minutes: ‘This is what your son or daughter is doing, this is what we want to do, sign here.’ But they know I’m not going to sign anything that day. They don’t know how to add enough room on their preprinted documents for me to write what I need to say.”

Through Partners in Policymaking, Brian learned that the law clearly states what is and isn’t admissible in an individual education program and what his rights as a parent are. The people in charge get nervous when you know more than they do, he says.

Brian and his sister were instrumental in starting an inclusive Waseca County 4-H group. And now Brian has another plan up his sleeve.

“Whenever I get a chance, I sit in on a county commissioners’ meeting,” he says. “When they ask why I’m there, I say, ‘I’m after your job.’ I think the best way for me to help people with disabilities is as a county commissioner.” When a seat opens, Brian will be ready to run.



# Rijuta PATHRE

started looking at people with disabilities in a totally different light after her experience in Partners in Policymaking. “I never would have imagined my daughter taking horseback rides or going to Disney World. I would have said, ‘She wouldn’t understand any of that.’ But after Partners we did go to Disney World, and it was magnificent.

“We realized how much she understands, how much she got out of it. She sat in that wheelchair for nine hours and didn’t cry once. She was so happy the whole time, and it was amazing to realize her potential.”

Experience and confidence didn’t come quickly to Rijuta. For eleven years she took care of Minu alone while her husband, Sadanand, was working as a chemist at 3M. Partners in Policymaking changed her life—and her family’s life.

Partners taught Rijuta to recognize Minu’s capabilities. Minu was born with significant disabilities and has never been able to speak. Doctors told Rijuta that Minu wouldn’t live for a year. Just send her to an institution and forget about her, they said. Rijuta had higher hopes for Minu, but even she had been selling her daughter short.

Before she participated in Partners in Policymaking, Rijuta always assumed that, because of her husband's good job, the family wouldn't qualify for personal care assistance and other programs. She learned at Partners that she had many more rights than she had imagined, and she learned how to get them. When her insurance carrier wouldn't pay for a special chair Minu needed, Rijuta appealed and won.

Her dreams for Minu were expanded as well. "Minu became my symbol of hope, and I began to appreciate and enjoy her presence on earth as a gift. A gift I wanted to share with others."

Minu's inclusion in the local schools and in their metro-area community at large also was influenced by Rijuta's involvement in the Partners program.

"One reason inclusion is good is that a lot of parents who have children without disabilities feel that kids like Minu are going to take time away from their children," Rijuta says, "but think about how once you have all these kids



Rijuta and her daughter have a special bond.

The gentle love grows every day, and the fruit of that love fuels her advocacy for Minu and many others.



together, then their children see my child and others like her as a part of the community. We take her to the mall and to all sorts of places where she sees her friends and kids from school, and all the kids who have known her don't think anything about it. That's because they've grown up around her.

"Everybody's life has importance, no matter what their ability is," Rijuta says. "Minu is dependent on other people's care, but she has such stubbornness and willpower that she gets things done the way she wants. So she has power over her life. She cries, she smiles, she has facial expressions that tell people who know her that she doesn't like something—and then she has that big smile that makes everything worthwhile."

Rijuta is now on many boards and committees, including the state Special Education Advisory Council (SEAC). "We talk about policy, we make changes, and we see the results of those changes," Rijuta says. "I'm involved in the policy end because that's where everything starts. Citizens really do have a voice, and they can indeed make a difference. People say, 'You're just one person; you can't change the system.' Well, you *can* change the system."



# Tom SCHWARTZ

moved from Wisconsin to Minnesota and quickly discovered that something was missing. In Wisconsin, a children's waiver covered the costs of personal services for his son Nick, but no such waiver existed in Minnesota.

Tom started talking with legislators, requesting that they bring waived services to Minnesota.

Other parents around the state were working toward the same end. "I must have written a hundred letters and made a thousand phone calls," Tom says. "But it worked, because we got the waived services in Minnesota. If you're above the poverty line, you can't afford all the services that a special kid needs without going broke. The waived services enabled us to remain in our community and help get my son the supports he needs in that kind of environment."

Decisive action to effect positive change was nothing new to Tom, who was instrumental in figuring out what was wrong with Nick and opted for a radical and highly controversial surgery.



When Nick was born with a large red birthmark on his head, Tom's research turned up the fact that it is a key marker of the rare Sturge-Weber syndrome: overabundant capillaries at the outer layer of skin—and thus the mark—resulting in lack of blood and oxygen to the brain. At thirteen months, Nick underwent radical surgery to stop his seizures.

Overall, Tom says, Nick is a smart kid, and now he's about to graduate from high school—in part because Tom was determined to find a way around the roadblocks to get the best possible education and services for his son. And then he went on to help dozens of other parents.



Tom and his son enjoy each other.

He's a strong advocate and a very active parent, but the bottom line is that they enjoy each other's company.



Tom has served two terms on the Governor's Council. Partners in Policymaking, he says, was "a godsend." Partners offered not only information about systems and services, but also emotional support from other parents.

Proud of his advocacy work, Tom says that "we have created a different world. Kids like Nick now are in it, but they're not yet a part of it. That will come. Amazing things have happened in the past twenty years. In another ten or twenty years, we won't even talk about disabilities the way we do now."



# Terri<sup>•</sup>SCOTT

doesn't want special treatment—and certainly no sympathy—just because she has cerebral palsy. When she was growing up, Terri was constantly being told what she couldn't do. People would say, "I'm just trying to save you some heartache. Well, don't," says Terri.

"Everyone has heartache in their life."

After four operations, Terri walked with a limp, which made her the target of schoolyard pranksters and bullies. One of her brothers used to tell her she should cut off her weak arm. She got into fights with people who harassed her.

When she played tag with the neighborhood kids, her mother would warn her: "The other kids aren't going to let you tag them."

"And I'd say, 'Mom, those are the rules of the game!' The thing people should be thinking about is that I was playing at all," Terri says.

A *60 Minutes* segment about the famed violinist Itzhak Perlman, who had polio as a child, taught the eight-year-old Terri a significant lesson: People with disabilities can do anything, and they shouldn't listen to people who doubt them. Too often, Terri says, the world smothers potential with limited expectations.

As an African American woman with a disability, Terri has encountered plenty of prejudice, yet it hasn't made her bitter. It has strengthened her resolve to be a part of the world, to advocate for positive change, and to dream of a better future for people with disabilities.

Terri works at a Twin Cities music store and is writing a book about growing up with a disability. Having changed a classmate's view of her abilities—which also persuaded him to stop tormenting her—she now hopes to open many people's eyes about the potential of all people with disabilities.

"I want the next generation to know how this generation got along," she says. "I want people to look at people with disabilities and say, 'I don't see why



Life is busy and full for Terri.

She works at a music store, maintains her apartment, and is now writing her memoirs.

Partners was a key that unlocked lots of doors. What's next? Everything!



they can't write a book. I don't see why they can't teach a class.' We've all had some struggles. But we stand out for who we are, not what we are. That should be the moral of any story."

Many people today are still "in the stone age" when it comes to respecting people with disabilities, she declares, and they're unaware that their own lives could change in a moment. "You could be driving a car, just having a run-of-the-mill day, and all of a sudden, crash, you have a disability," she says. "Then you'd be shunned. You'd be an outcast."

Terri focuses on her victories—and on the potential of changing perceptions of people with disabilities. She once wrote to a publisher to take issue with a book's characterizations of what it's like to live with cerebral palsy, and the publisher promised to make changes in the next edition.

She's out there every day, blurring the lines between people with disabilities and everybody else. In her mind, there is no line. Her next goal is to change *your* mind.

"I would like people to see that just because we have a disability, that doesn't mean it should be the end of the world for us," Terri says. "It's the beginning. It's a triumph for us. We're part of the community. We're out there doing stuff. And to think that fifty years ago they were putting people like us away in institutions."



# *Dan* SHAFLAND

has struggled with the exhausting condition known as stuttering for more than fifty years. Many impatient listeners walk away and stay away, but they're missing something: this man is well worth listening to.

“It is so easy for ‘us’ to give in to other people’s expectations,” Dan says. “I have, for years. I suggest we can and should set our own goals and objectives and have at it. Then possibly we would no longer be ‘disabled.’ ”

Meeting difficulties with strength of character, Dan ignored high school counselors who told him he shouldn’t even think about going to college. Undaunted, he enrolled, intending to become a minister—like his father. School officials discouraged him. Well, then maybe he would be a doctor. Can’t, they said. A veterinarian? Same thing: he would still have to deal with people.





Dan began to stutter when he was five. “I think how it starts is people say, ‘No, speak clearly,’ and you begin to be more concerned about how you talk,” Dan says, “and the more concerned you are about how you talk, the more you have trouble doing it. My parents did everything they could to help. They had me go to therapists and doctors, and in some ways I think that made it worse.”

A few years back, Dan went to a Partners in Policymaking class that helped him become more assertive and confident in getting services to which he is legally entitled.

“Partners helped me see that I can do things. They helped me see that I have to stand up and fight,” he says, shaking a fist for emphasis. “They helped me with self-esteem and told me to go deal with the agencies and tell them what I expect.”

When friends with disabilities run into barriers, Dan always tells them about Partners in Policymaking.

“Do you know how you feel when they hand you a degree?” Dan asks. “You say, ‘Okay, I’m comfortable with things.’ That’s how I felt at Partners.”

“They told me I should go work with the Forest Service,” Dan says.

Not about to go off into a forest, Dan went on to study biochemistry, then medical technology. He married, moved to northern Minnesota and got a job in a hospital, where he was in charge of the lab for many years.

Dan is haunted by a nagging feeling that his primary disability through the years has not been stuttering, but rather the bigotry of others. A healthy sense of humor has helped.

“People TALK TO ME LIKE I CAN’T HEAR,” Dan says loudly, then adds, “I have a speaking problem, not a hearing problem. Some people think I’m on drugs. Some people just laugh at me.”



Life is full and adventurous for Dan. He loves to travel, read, and explore cultural and spiritual interests.

# Bonnie Jean SMITH

claims that information is power, but you have to add action to any equation. “I got information from advocacy groups and from Partners, but I still have to do the work to make things happen.

“Everything I’ve been through in my life is getting me ready for my Goliath, whatever it may be,” Bonnie Jean says. “I believe everything in life has a purpose.”

In 1995, her middle sons, Donnie and Richard, inhaled lead dust at the house the family rented. Doctors said Richard could have died if he had been tested a few days later. They could make no predictions about the boys’ future.

The boys’ schools insisted that they had emotional and behavioral disorders when in fact they had lead poisoning. When Richard was in kindergarten, he allegedly tore up a room with scissors.

School administrators asked Bonnie Jean to sign a document stating that she wouldn’t bring Richard back to the school and would allow him to be placed

elsewhere. Without knowing her rights and her son's, she signed. Only later did she find out that she didn't have to—and later still, that Richard wasn't physically able to do what he had been accused of doing.

“I was so angry I called up the president of the United States,” Bonnie Jean says. She e-mailed her congressional representatives and the governor.

Her calls ultimately got her connected to advocacy organizations, and she took a job with a new high school program for kids with emotional and behavioral disorders.

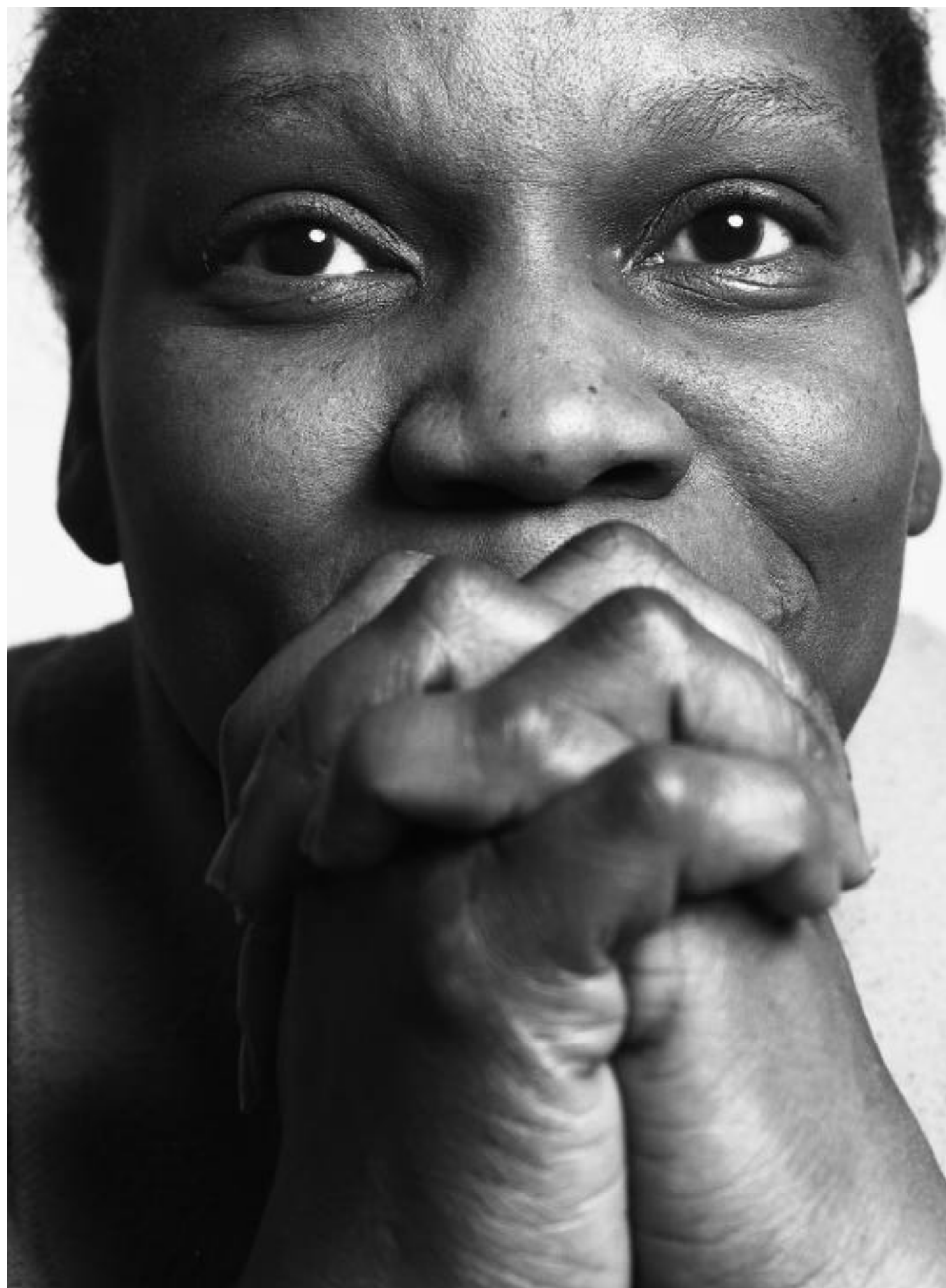
When she was put in charge of detention, she wanted to keep the troubled kids from dropping out and to teach them lessons in spite of themselves, so she made detention fun instead of punitive. “I had the geniuses of the school science program playing Scrabble with kids with disabilities and gang-bangers,” she says with a hint of pride. “Everybody can be included. Everybody can add to the community.”

She had a great deal of firsthand knowledge about kids with developmental disabilities but didn't quite know what to do with it. Participating in the Partners in Policymaking program closed the gaps.



Bonnie is a committed and loving mother with a home life that focuses on books, music, dancing, and art.

It has always been about inspiring, educating, and supporting her children (Bonnie, shown with her sons, also has a teenage daughter).





“If you’re looking to be an advocate, you cannot get better training than Partners,” she says. “I learned how to get a bill through the legislature. I found out that I have a right to do that as a citizen of the United States. I found out that if I didn’t like something that was going on, I could write any government person or agency and get an answer back. Sometimes you get a form letter, but a lot of times I get a real letter that’s specific to what I’m talking about.”

Now she is an advocate for parents of children with disabilities, helping them clarify their visions for their children’s educational programs. And she is a member of the Minnesota Governor’s Council on Developmental Disabilities.

Bonnie Jean has pushed for full inclusion in school classes for Richard and Donnie. She doesn’t want them segregated in a special-needs class. “They don’t live in a segregated neighborhood,” she says. “They don’t go to a segregated park or a segregated autism YMCA.”

Partners in Policymaking helped Bonnie Jean realize that her sons have the capacity to become productive members of society and opened her eyes to the value of setting them on a path toward independence.

Ironically, letting go of them may be the most difficult fight of all.

“I know that it’s going to be hard, but it’s something I have to do,” Bonnie Jean says. “You let that butterfly go.”

Author Lee Roberts, a graduate of the journalism school at the University of North Carolina at Chapel Hill, spent ten years working for the New York Times Regional Newspapers Group before becoming a stay-at-home dad and freelance writer.

Designer Linda Beauvais has worked on graphic projects for the Governor's Council on Developmental Disabilities for over eighteen years. She counts the Council projects and people to be among her favorite work.

Photographer Ann Marsden is a fine artist as well as a commercial photographer. Touring the state to photograph the people in this book was a dream job. She thanks the graduates for welcoming her into their lives.

Editor Lynn Marasco works for a number of magazine and book publishers. This is her first project with the Council.

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